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Informed dissent

SIR:

Alison Davis's principle concern is with the Right to Life; mine, is with the Duty to Care (1). I am quite prepared, for the purpose of this debate, to accept that all people have an equal right to life. But, if some require 24-hour care in perpetuity in order to exercise this right, the brutal practical question arises as to who is going to undertake this task? After all, carers too have a right to life, and a lifetime of compulsory caring effectively deprives many of them of the right to a life worth living, as my own and several other recent studies have suggested.

Until recently, the answer was obvious. Of course, the parents had a duty to care. In practice, of course, parents nearly always means mothers. Now we may be witnessing the start of the 'Revolt of the Mothers'. Some, at least, have decided that a lifetime of caring is intolerable.

Society's response has been to offer a fair amount of assistance while their severely mentally handicapped children are of compulsory school age, but very little help thereafter. A few outings to the 'club', occasional respite-care booked weeks ahead, if they are lucky, and so on. None of this frees them to live an independent life. All it does is give them an occasional break in order to prepare them for the next round of caring.

If they can no longer cope, then according to Alison Davis, they have the option of adoption. This, unfortunately is not so. Although it is

possible for some moderately handicapped and younger children to find adoptive parents, hardly any very severely mentally handicapped children do so, least of all the older ones. Most languish in institutions if their parents cannot keep them. The reputation of many of the large mental handicap hospitals leaves something to be desired, and scandals about the treatment of patients in them are a subject of recurrent public and parliamentary concern. On June 10 1986, to take but the most recent example, Mr Dennis Canavan MP opened a debate in the House of Commons on Mental Handicap (Hospital Conditions) (2) in the course of which he referred to:

'... the filthy conditions, the dilapidated buildings, the overcrowding, the lack of basic amenities and the severe staff shortages in institutions which are supposed to care for some of the most deserving people in our society ...'.

Most parents know all this only too well and understand that effectively they have no choice but to 'care' because they are not being offered any civilised or acceptable alternative.

The Government's determination to control public spending means that this situation will deteriorate rather than improve. And it must be said in all honesty, that if there were indeed more public money available many would prefer to spend this on making hip operations more accessible, or on other good causes.

In this connection I note with wry amusement the Delphic utterance of your contributors J K Mason and D W Meyers in the same issue of your journal also writing about deformed newborns:

'The burden on the family is not a matter that physicians should be compelled to evaluate or act upon. The allocation of scarce treatment resources in such cases is a real limiting factor but is one which is imposed by factors beyond the control of physicians or parents – as well as being beyond the scope of this article' (3).

The purpose of my article was to suggest that this tunnel vision really won't do any longer, and when the 'carers' ie the mothers, finally demand their own right to life, the physicians will finally have to make contact with the real world that exists out there, beyond the pages of the journals, philosophical and medical.

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Mental Health and Human Conscience, the True and the False Self (Gower 1984)

SIR

Dr Stephen Little's review of my book in the June 1986 issue of the journal, pages 97–98, misinterprets my views in two vital respects:

(1) I am not 'much influenced by Romantic notions of the true self', but I consider the recognition of the true and the false self as manifestations of a person's conscience. This (non-theistic) interpretation of conscience is to me the most powerful antidote to today's malaise of cynicism and despair.

(2) I am not 'content to categorise as "illness" what cannot be appealed to'. Rather is 'a person suffering from a psychotic illness treated existentially [with an appeal to his conscience and freedom] to the extent to which his illness makes such treatment possible', page 147. The 'boundaries of and rationale for this division' [into those with and those without freedom] are explored in the section entitled 'existential assessment', pages 147–149, and are illustrated by the case of 'Anna', pages 122–125. Therefore this 'central issue' is not avoided and 'the applicability of [the] entire theoretical stance' is not threatened.

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